

To The Finance, Revenue and Bonding Committee (4-23-15)

Hello. My name is Terry. I live in East Haven as a single parent raising Mikey, who is my 15-year old disabled son. Mikey is a special needs student who attends Oak Hill School. He requires a high level of daily living adaption skills and extensive monitoring and supervision. Mikey is non-verbal, autistic and developmentally delayed in all areas of daily living/gross and fine motor skills (requiring incontinent care as well).

As you may imagine, getting through a work week has become quite a chore. I rely heavily upon the resources I do have in place right now through DDS and cannot imagine having even one piece cut out. I would not be able to maintain gainful employment.

One of the greatest problems I am having right now with my son is his inability to communicate his innermost feelings and the deeper thoughts that cannot be communicated successfully through an augmentative communication device. It is not only frustrating for him, but becomes equally as frustrating for those who are trying to understand him. We continue to struggle with this daily. His receptive language is right on target, yet he is unable to engage in any meaningful conversations with anyone. Stop for one minute and imagine your own life like this—not being able to speak—at home, at school, at the doctor, no friends; sometimes he just runs for the door, or jumps up and down uncontrollably or becomes quite loud vocally (not verbally). The frustration can take on many forms and you must be ready for it. Other times he just engages in the same repetitious phonetic sound (usually representing the same word) over and over again. I must respond just as many times as he vocalizes it; in essence, I take on the same characteristics of his disability when interacting with him.

The other huge issue is toileting. I am having great difficulty when in public places when he needs to use a restroom. It has come to a point in time whereby he can no longer accompany me to the ladies' room nor can I go with him to the mens' room to assist him. This is embarrassing and for many people crosses that line of acceptable norms in a developed society. For example, the female teachers do not assist him to the boys' restroom at school. At school, there is a definite plan in place so that it is a male teacher's aide that assists in this aspect of his special needs. Nonetheless, we continue to struggle daily with the ramifications of this dilemma when in public places.

He has however, made some great strides with the help of his school, teachers, and other caregivers that are willing to go the extra mile. He is learning how to type letters in the google search and to pull up information. He copies the letters one at a time from a paper. He is unable to write so this is a great milestone I am hoping will continue to expand. As his primary caregiver, I continue to be both his advocate and his voice, which now prompts me to the next issue.

It stuns me that in this year of 2015, living in the state of Connecticut, with so much advancement in worldly possessions and technologies, there is no money, no plan and no ethical boundary for the future welfare of our loved ones who cannot care for themselves. They are simply expected to live with us until we are medically no longer able to care for them or we ourselves expire. What happened to the long standing policies and paperwork that we filled out for years at the onset of a new school year dictating an emergency plan for our children. We as caregivers, have spent a lifetime, along with all of our team players such as doctors, school teachers, case workers, caregivers, etc. taking baby steps to get our children to where they are today—we have taken such pride in our accomplishments and have done so much for our children. My child will regress if there is not an adequate plan in place for him as he ages out of the school system. The day programs offer a viable alternative once this happens. He will regress right back to square one in no time at all with the absence of such a program. That is why the summer school programs are such an imperative component of the IEPs for these students. It avoids the interruption and hence the regression that would follow if it were not part of the

IEP. The very nature of the disability of autism has a primary characteristic that resists change; the essential approach to all treatment involves consistency and that is exactly what has been implemented across the board from all team members. The day programs that these children transition over to offer this element of consistency in their lives. I know immediate regression would be inevitable for my child if his programs were to cease or diminish, and he was left with no alternative but to stay at home.

The Department of Developmental Services has developed a comprehensive, mandatory online training program for all perspective caregivers. The introductory segment of this course gives a very vivid portrayal of how the disabled community was regarded back in the early years. It goes through the different eras with an emphasis on how dignity and respect is so crucial today. It points out how easily these people can be targeted and taken advantage of in many ways, shapes and forms. It mandates the reporting of abuse of all forms—physical, emotional, financial, etc. It very clearly communicates the unethical mentality that existed early on in our society will no longer be tolerated today.

How ironic—because the proposed budget cuts are speaking loud and clear. The very mentality that DDS is trying so hard to eradicate through its training and teachings is prevailing. The cuts, simply stated, are saying these members of our society are not worth the time, the money or the planning for. Whatever happens, happens. This is WRONG!!

As far as the waiting list for DDS clients, dealing with my death and my absence from his life would, in itself, be more than my son could handle; to think that this state will only intercept in the event of my death is unacceptable; to expect these special individuals to be able to transition into a residential facility only upon death or incapacitation of their caregivers is to do nothing less than sentence them to a double jeopardy. My son would go right back to square one with his unique disabilities; this is totally unacceptable and unjust. In fact, resistance to change is one of the classic characteristics of autism and is at the core of this disability for many on the spectrum. So the current plan, to only find residential placement upon our death, certainly disregards the very nature of the disability. What was all of our work for, and the money that was spent thus far? For nothing?? And to think of the unforeseen situations and predicaments that will surface is unimaginable as this State attempts to compromise the safety and well being of these individuals by slashing this very sensitive budget that should be protected at all times—at all costs.

I know my time is running out—he is 15 years old—that is just 6 years away from aging out of the school system. With each passing day I grow more fearful of the bleak future he faces alone without me. It remains an unethical tragedy that in a state so advanced in so many areas, Connecticut still chooses to look the other way. Ironically, the mandatory training that DDS imposes upon caregivers of its clients teaches us of this era in time and how unethical it was. Yet this same unethical mentality still stands at the core of the issues we are fighting for today—CEASE FUTURE CUTS TO DDS and ALLOCATE FUNDS MORE EFFICIENTLY AND EFFECTIVELY TO REACH THE MAXIMUM NUMBERS OF CLIENTS WHO ARE COUNTING ON YOU WITH EVERYTHING THEY HAVE. OUR FAMILIES CAN'T WAIT. PLEASE—

STOP THE CUTS TO DDS

Please consider all of our children and our families when making the decisions that will ultimately impact our futures for a long time to come. We need your help and we are counting on it today.

Thank you for your time, and for listening to us today.

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